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Title

The effect of a dysfunctional upper-limb on community dwelling stroke-survivors and their carers: An interpretative phenomenological analysis.

Abstract

Objectives:

The post-stroke upper-limb continues to pose a myriad of physical and psychological challenges for patients and caregivers. To optimise existing services, this study firstly aimed to explore the experiences of both stroke survivors and caregivers, and secondly identify their ongoing needs.

Methods:

A qualitative approach was utilised for this study. Six participants (3 stroke survivors and 3 caregivers) were purposively sampled from community stroke groups. Semi structured interviews were utilised to collect experiential data, which were analysed using an interpretative phenomenological approach.

Results:

Three master themes emerged from data analysis: ‘Finding a way forwards from a poor start’, ‘The battle with the upper-limb’ and ‘Relationships with self and society’. All participants, seemingly affected by disappointing services, expressed negative views of rehabilitation. Misplaced or persistent hope, losses in control and reduced autonomy may have contributed to poor functional outcomes and perceptions of rehabilitation services. The complex

physical and psychological impact of the experience of the dysfunctional upper-limb was also associated with ongoing and unmet support needs for stroke survivors and carers.

Conclusions:

Healthcare professionals may consider the varying impact of the dysfunctional upper-limb during decision-making and treatment planning, particularly during acute rehabilitation. Future research could explore therapists' perceptions and experiences of upper-limb rehabilitation during this period.

Keywords: Stroke, Qualitative, Rehabilitation, Dysfunctional upper-limb

Introduction

Stroke is estimated to be the largest cause of adult disability in England (National Audit Office, 2010). The majority of stroke survivors experience persistent upper-limb impairments, with only half regaining functional use after six months (Kwakkel et al., 2003). Ongoing physical and psychological sequelae include detrimental effects on activities of daily living (ADL's), independence (Faria-Fortini et al., 2011), changes in role and impaired wellbeing (Wiles et al., 2002). This physical and psychological impact is evident in research demonstrating stroke survivors' unmet needs and reduced health-related quality of life (HRQoL) (Morris et al., 2013). Additionally, caregivers also undergo adjustment, resulting in emotional distress, impaired HRQoL and unmet needs (Buschenfeld et al., 2009).

Identifying ongoing needs and understanding how such needs may underpin HRQoL could contribute to optimising HRQoL, an aim of the National stroke strategy (NICE Guidelines, 2013). Further, systematic reviews regarding interventions for restoring the functional ability of the upper-limb reveal inconsistent effects on HRQoL (Pollock, Farmer, et al., 2014; Pulman & Buckley, 2013; Pulman et al., 2013) and identify a lack of adequate focus on relevant psychosocial constructs (Murray & Harrison, 2004). Directing attention to unmet needs and HRQoL could theoretically help optimise existing interventions (Pollock et al., 2014). However, relatively few qualitative studies have specifically explored experiences associated with a dysfunctional upper-limb (Barker & Brauer, 2005; Connell et al., 2014; Doyle et al., 2014). Such research has suggested a disparity between acute upper and lower-limb

management. However, stroke survivors' ongoing needs and potential factors for limited efficacy of current upper-limb rehabilitation remain unexplored.

Research regarding caregivers' role also indicates changes in role and adjustment to post-stroke life occur (Bulley et al., 2010; Buschenfeld et al., 2009). However, the contribution of the upper-limb to these constructs has not been fully examined. Indeed, no qualitative studies have specifically explored caregivers' experiences pertaining to the dysfunctional upper-limb, despite caregivers ascribing relative importance to upper-limb recovery (Pollock et al., 2014).

Multi-perspective interviews are advocated to explore dyadic relationships on the basis of accessing phenomena from more than one perspective (Kendall et al., 2009) and thus also acting as a form of triangulation. No studies have evaluated both caregivers and stroke survivors experiences of the dysfunctional upper-limb, although caregiver and service user interviews have previously examined relationships and ongoing needs in other areas (Kendall et al., 2009; Jones & Morris, 2013). Therefore, given the paucity and limitations of the current literature, this study aimed to investigate the experiences and ongoing needs of community dwelling stroke survivors with a dysfunctional upper-limb, and their caregivers.

Methods

Design

Phenomenology seeks to provide an account of lived experiences, thus making it a suitable methodology of choice. Interpretative phenomenological analysis (IPA) seeks to explore participants' perceptions of their experiences. It emphasises an interpretative stance, in that the researcher aims to understand the participants' experiences who is in turn trying to make sense of their own experience (Smith et al., 2009). To adequately explore the meaning of an experience, each account is examined in detail, focusing on depth rather than breadth of data, therefore typically employing smaller sample sizes (Buschenfeld et al., 2009; Connell et al., 2014; Hunt & Smith, 2004; Murray & Harrison, 2004).

Sampling and Participants

Purposive sampling was used to obtain a homogenous group of participants. Eight community stroke user groups in south and north London were contacted. Those with an upper-limb which remained dysfunctional, were over 18 years of age, at least 6 months post-stroke, and with a caregiver consenting to be interviewed, were provided with written information. A 'caregiver' was defined as a partner, family member or relative providing primary care. Individuals with language or cognitive difficulties precluding consent or interview participation were excluded.

Ethics

Approval was obtained from King's College London (BDM/14/15-30).

Topic guide and Patient and Public Involvement

Separate topic guides were developed for stroke survivor (Supplementary Material S1) and caregiver (Supplementary Material S2) interviews, with reference to IPA guidelines (Smith et al., 2009) and feedback from a Stroke Patient and Family Research group. Topic guides adopted a funneled structure beginning with general, and ending with specific questions (Paterson & Higgs, 2005). A pilot interview, not included in the final analysis, was completed.

Data collection

Semi-structured interviews were utilised to gather in-depth data. Questions were broad and open-ended, with prompts to encourage further depth (Ritchie & Lewis, 2003). Interviews were conducted at participants' homes, separately, but within the same visit, were audio-recorded and transcribed verbatim. Interview duration ranged between 35-85 minutes and lasted on average 52 minutes.

Analysis

All transcripts were analysed individually using guidance from previous IPA work (Eisikovits & Koren, 2010; Smith et al., 2009). Cross-case analysis was performed across all stroke survivor and carer transcripts, whereby superordinate themes were abstracted into overarching master themes (Supplementary Tables S3). Dyadic analysis is somewhat distinctive as it requires examination of overlapping and contrasting emergent themes from

each pair of participants, rather than exploring such convergence and divergence amongst individual participants.

Results

Findings are reported in accordance with COREQ guidelines (Tong et al., 2007). Three stroke survivors and three caregivers participated. Table 1 and 2 highlight the respective characteristics of stroke survivors and caregivers. Subjective and objective scores of upper-limb specific outcome measures are presented (Supplementary Table S4).

Table 1 Stroke survivor characteristics.

Table 2 Caregiver characteristics

Three master themes emerged from data analysis (Figure 1): Finding a way forwards from a poor start; The battle with the upper-limb and Relationships with self and society. This is a hypothetical model and it is unclear whether these processes occurred in a chronological or parallel manner.

Figure 1 Hypothetical chronological representation of master themes

Finding a way forwards from a poor start

All participants reported a ‘poor start’ to upper-limb rehabilitation, with the arm seemingly neglected by clinicians in favour of the lower-limb with the aim of improving independence and mobility.

“I wished they’d done more for my arm...for the arm very little…it was all concentrated on getting you walking again…so you can go to the bathroom by yourself” [Mary, stroke survivor]

Mary appeared to divert responsibility away from herself for this decision, reflecting her disappointment in the functional outcome of her arm and the loss of autonomy she perceived during her rehabilitation. A lower-limb focus was also associated with facilitation of discharge and perceived improved psychological and emotional wellbeing. This lower-limb emphasis in rehabilitation continued in the community setting and was exacerbated by perceived inadequate provision of and a delay in, receiving upper-limb interventions.

“I maintain if they had come out quicker I would have had more input on my arm” [Amy, stroke survivor]

Perceived insufficiencies in upper-limb rehabilitation were linked to dissatisfaction in functional outcomes, with associated frustration. Poor information regarding recovery potential not only detrimentally affected participation in rehabilitation, but also led to ongoing hope and perhaps unrealistic expectations of returning to ‘normal’.

“It wasn’t pointed out sufficiently…her doctor didn’t explain clearly to me that the arm was the most unlikely one to come back” [Neil, carer]

"We have to help him so that he will be able to use his left hand as he used to use before" [Amelie, carer]

In some cases, this hope appeared somewhat futile and invoked emotional turmoil and disappointment. Despite this, carers displayed ongoing hope in the face of unchanging function, alluding to the psychological benefit of hope.

"Hope was all on this bloody glove…it's not going to work, it cannot work…so I wish we hadn't had it…so I copied that in plastic [a glove]. And let's hope maybe she can learn to do some tricks that, that have the air of functionality" [Neil, carer]

These inadequacies and the associated disappointing upper-limb outcome led to unmet needs. For example, caregivers desired increased independent time and support to relieve the burden associated with caring, whilst stroke survivors' immediate needs focused on upper-limb recovery. Although both caregivers and stroke survivors' longer-term needs shifted towards improved participation and social interaction, caregivers also desired more independence and free time.

The battle with the upper-limb

All participants viewed the dysfunctional arm negatively, largely due to negative perceptions of impairments, difficulties with ADL's and participation. Stroke survivors and caregivers perceived a large degree of disembodiment

of the arm, which alongside the perceived 'death' of the upper-limb, appeared to cause a vicious circle of passive neglect, non-use and poor function.

"It just looks dead where she can't move it and it just hangs" [Dan, carer]

The persistence of stroke survivors' upper-limb impairments hindered ADL's, with associated embarrassment and frustration. Within some transcripts, discordance was noted in stroke survivors' ability to complete tasks of daily living and their request for help with the same task, representing an internal struggle between independence and dependence.

"Yeah I can dress but if I want to button um my shirt or something I don't button it very well… I make a mistake…it takes me time" [David, stroke survivor]

"I can't button my shirts, she (carer) help me with that" [David, stroke survivor]

Amelie, David's caregiver, also alluded to this internal struggle. Although she acknowledged David's ability to complete upper-limb tasks, she demonstrated her desire to help him, perhaps further restricting his independence by becoming overprotective. Upper-limb impairments also limited stroke survivors' community participation with associated psychological impact.

"You need two hands to really to turn over the music so I have to have a music stand which means…everyone else stands and I sit…when they stand up to sing they cast shadows all over my music…I hate being this sort of object of people's pity" [Mary, stroke survivor]

Due to the increased burden of caring for stroke survivors experiencing upper-limb dysfunction, caregivers reported a reduction in independence and fractionation of their time, with resulting emotional impact.

"Do the cooking, all the housework…she can just about dress herself …the main change in role is that my timetable is now punctured in many ways…My bubble's being busted and I'm beginning to resent that…I go grumpy and I'm quite a nasty piece of work...like having a bear in the house." [Neil, stroke survivor]

Neil portrayed his life as a fragile balloon, vulnerable to puncture by Mary's needs and requests, whilst further demonstrating his psychological and emotional burden by likening himself to a bear. Stroke survivors also demonstrated a loss of independence, control and autonomy, associated with significant psychological burden.

"When you're little you can't do your shoe laces and then I'm an adult now and I can't do my shoe laces…I don't really get frustrated or angry I s'pose it's just depressing" [Amy, stroke survivor]

Relationships with self and society

Some stroke survivors perceived a change in role from independent adult to dependent, child-like personas, secondary to their upper-limb dysfunction reflecting a loss of independence and autonomy.

"I can't dry my hair, make up, my friend does it for me…how am I meant to dry my hair with one hand...bathing would be difficult but the carers help me with bathing…I feel like a child" [Amy, stroke survivor]

Other stroke survivors perceived changes in role to be synonymous with an inability to achieve future goals. David portrayed an image of 'packing' away his knives, depicting his old career and inability to work specifically in relation to the function of the upper-limb, causing emotional burden and reflecting his perceived lower societal position.

"I used to be a chef. Yeah but they tell me that if I am trying to cook…they tell me don't do that otherwise you might cut [his arm], so I packed all my knives, the sharpest, I packed them away" [David, stroke survivor]

Caregivers meanwhile perceived themselves in a service-type role, reinforcing the struggle between promoting stroke survivors' independence but also becoming overprotective and thus reinforcing their dependence. Changes in role also affected relationships between stroke survivors and their caregivers'.

Dan reported role reversal, becoming the protective adult, with his mother Amy, the vulnerable dependent,

"She can't open jars cos she's only got one arm and hand, she can't even take the lid off the milk and hold the milk at the same time…she relies on me a lot" [Dan, carer]

Mary and Neil's relationship became infiltrated with guilt, resentment and psychological fatigue following inequality in domestic chores and a resulting power shift. Stroke survivors' relationships within the wider society were also subject to change, seemingly due to cultural stigma. Amelie and David portrayed stroke as a 'curse' or a supernatural, contagious disease, driving away family and friends.

"Sickness is a terrible stigma among our people. I have lost every friend. I don't have any friends…sometimes you feel whether you have been cursed" [David, stroke survivor]

Abandonment resulted in sadness, isolation and restricted participation. Whilst David accepted this situation, Amelie was less forgiving and subsequently restricted his social interaction. Social stigma was also evident in some stroke survivors' accounts, resulting in avoidance of social occasions, underpinned by an unwillingness to explain the arm's physical appearance and functionality, causing further restriction and isolation.

Discussion

The primary focus of this study was to investigate the experiences and ongoing needs of stroke survivors with a dysfunctional upper-limb, and their carers. Three master themes are discussed below.

Finding a way forwards from a poor start

The disappointing outcome of the dysfunctional upper-limb was strongly associated with negative experiences and perceptions of upper-limb rehabilitation, findings corroborated by previous literature (Bulley et al., 2010; Kendall et al. 2009). Similarly, a lower-limb rehabilitation emphasis, seemingly reinforced by its association with early discharge, increased independence and improved emotional wellbeing, was also blamed for a poor upper-limb outcome. Hospital or therapist related discharge priorities (Chouliara et al., 2014) may have heightened this focus, whilst a loss of participants' autonomy within decision-making may have resulted in blame and deflection of responsibility towards medical professionals for negative outcomes (Eccleston et al., 1997). A review of general stroke rehabilitation also highlighted the association of negative rehabilitation experiences with a lack of autonomy in stroke survivors (Luker et al., 2015), and suggested feasible strategies such as optimising communication and using collaborative goal setting to counter this.

Inadequate information regarding recovery during early rehabilitation was also perceived to have led to ongoing and perhaps unrealistic hope, seemingly contributing to increased psychological burden, but conversely also acting as

a source of positivity. The role of inadequate information within the theme of ongoing hope appears controversial (Maclean et al., 2000; Wiles et al., 2002), perhaps because hope is ontologically defined (Paley, 2014) and exists intrinsically, thus differing between and within individuals. Although previous studies have reported unrealistic hope to be detrimental to recovery and psychological health (Alaszewski & Wilkinson, 2015); research also demonstrates dismissing all hope may negatively impact wellbeing, with hope providing motivation and strength through recovery (Barker & Brauer, 2005). Therefore, although adequate information is required for decision-making, the likely impact of this on the development and maintenance of realistic or unrealistic hope remains unclear. There may be a need for an evidence-based pathway, particularly for stroke survivors with a poor prognosis, to guide healthcare professionals in 1) providing sufficient information and 2) to collaborate more effectively during clinical decision making with stroke survivors and their carers.

All participants identified unmet needs, even many years post-stroke. Such needs were largely attributed to the perceived inadequate rehabilitation received post-stroke. It is unknown whether the services did indeed meet required standards (NICE Guidelines, 2013) or whether services were sub-optimal. Future work aligning such perceptions with service provision would be insightful. Stroke survivors identified immediate needs relating to upper-limb motor recovery, similar to those identified elsewhere. Indeed, Reed et al. (2010) explored the experiences of stroke survivors participating in an intervention comprising of exercise, goal setting and stroke specific

interaction. Interestingly, participants appeared to most value factors including knowledge acquisition and elements which gave them the greatest amount of control, in contrast to their initial aims of improving their motor function. Although the generalisability of these findings was limited by response bias, conclusions may be pertinent to stroke survivors experiencing a dysfunctional upper-limb, given the perceived loss of control noted in this study, and the significant upper-limb related psychological burden.

Caregivers identified psychological and physical support needs to reduce the burden of caring and increase their independence. However, caregivers appeared to feel uncomfortable divulging such information, and thereby devalued their needs perhaps due to the societal norms and expectations of caring (Harper & Levin, 2005). Previous research in stroke has identified needs pertaining to improved support (Greenwood et al., 2009) and information regarding local services (Hare et al., 2006), themes noted in this study. It would seem the persistence of upper-limb dysfunction continues to place a heavy burden on both stroke survivors and their carers, supporting the case for improved community interventions to optimise long-term quality of life for both parties.

The battle with the upper-limb

Participants voiced negative upper-limb perceptions, resulting in disembodiment of the arm and significant emotional burden. A health psychology view suggests perceptions are formed by past experiences (Marks et al., 2005). This reinforces the significance of participants'

perceptions of inadequate upper-limb rehabilitation noted in this study. The impact of such negative perceptions is noted in Leventhal's model of self-regulation (Leventhal et al., 2001), which provides a framework to better understand how personal experiences influence perceptions of illness, subsequently guiding illness related behaviours. In the current study, negative perceptions appeared to impact behaviour in a vicious cycle of passive neglect, non-use and poor motor function, resulting in disembodiment of the limb. Given the time since stroke, such disembodiment is seemingly a persisting consequence, reflecting limited physical and psychological ownership of the arm and thus warranting adequate psychological strategies to address this. self-management strategies could be usefully employed here, with the support of carers.

The upper-limb impairments noted are similar to those reported elsewhere, adversely affecting ADL's (Carod-Artal et al., 2009) and HRQoL (Nichols-Larsen et al., 2005). Within the transcripts of David and Amelie, an internal struggle between desiring independence and being overly-dependent or becoming overprotective was identified. Stroke survivors' over-reliance on their carer could be due to acceptance of a 'sick role', whereby patients are exempt from normal social roles and responsibilities (Larsen & Lubkin, 2009). Although such roles are normally aligned with acute conditions, variants have been suggested in reference to ethnicity and age (Twaddle, 1969), perhaps explaining this divergence. Previous research has attributed caregiver overprotection to fear (Buschenfeld et al., 2009); however, this was not noted in the current study. More noteworthy, is research suggesting ethnic

differences may influence caregiving behaviours and access to support (Dilworth-Anderson & Gibson, 2002; Pinquart & Sörensen, 2005). The role and contribution of overprotection or over dependence on determining functional upper-limb outcomes is not yet clear.

Further psychological burden was engendered by losses in independence, choice and autonomy for stroke survivors and caregivers, findings noted previously (Salter et al., 2008). Research has also demonstrated loss of control to affect selection and use of coping strategies (Sand et al., 2008), whilst autonomy is posited to be one of three psychological needs within the self-determination theory, in turn thought to be the basis for optimal psychological functioning (Ryan & Deci, 2000). Such findings may assist health professionals in their stance during decision-making and treatment planning.

Relationships with self and society

All participants reported changes in role alongside their upper-limb deficits. Some stroke survivors reflected their upper-limb related dependence and loss of control in a child-like persona. Although changes in role were noted in other general stroke studies (Pringle et al., 2013) they did not specifically concern regression to child-like roles, perhaps reflecting the highly increased dependence associated with a dysfunctional upper-limb. Other stroke survivors related upper-limb impairments and an inability to work to a change in societal position. Previous research is in agreement on the psychological impact and the possible detrimental effect of changes in role on adjustment

post-stroke (Sarre et al., 2014). Adjustment to the post-stroke self appears significant in relation to HRQoL and seems influenced by a variety of constructs including the ability to cope with losses in control or autonomy (Walker et al., 2004), thus further emphasising the importance of these themes. Carers also identified changes in role, perceiving themselves in primarily a service-type position, causing resentment, anger and frustration. Previous research has noted gender to impact such changes (Greenwood & Mackenzie, 2010) although ethnic differences appeared to impact role more notably in the current study.

Changes in role were also evident in relationships of caregivers and stroke survivors. Some identified role reversal, whilst others reported inequity in household tasks or power, engendering negative emotional reactions and psychological burden. Although other studies identified similar themes, benefits of mutuality and personal growth were also demonstrated (Buschenfeld et al., 2009; Hunt & Smith, 2004; Murray & Harrison, 2004), themes not evident in the current study. This may represent the differing ages and ethnicities between samples, or the added burden of the experience of a dysfunctional upper-limb. Banks & Pearson (2004) noted role changes to impact family functioning, whereby members became reluctant to divulge their feelings due to guilt or resentment. We identified similar findings in the carers' interviews, signaling the need for adequate support and communication between stroke survivors and their caregivers. This reluctance to divulge their feelings may also hinder their access to support services. Relationships within the community were also affected with both participants reporting restricted

social participation, and associated isolation, loneliness and reduced HRQoL (Buschenfeld et al., 2009; McKevitt et al., 2004).

The benefits of multi-perspective interviewing were noted within David and Amelie's accounts of cultural stigma. Stroke was identified as a supernatural affliction, resulting in abandonment and isolation, influencing stroke survivors' HRQoL and caregivers' burden. Although relatively few studies exist on stigma and stroke, similar observations have been noted (Helman, 2007; Jacoby, 2002). However, authors postulated stigma is complicated by discordance between participants' subjective perceptions of disability, and more objective health status (Albrecht & Devlieger, 1999), themes noted in this study. Caregivers and stroke survivors also identified social stigma, influencing stroke survivors' participation and leading to overprotection by caregivers. Given the role of information in acceptance and delineation of stigma (Asbring & Narvanen, 2002) further research exploring the feasibility of providing more information to both caregivers and stroke survivors may be warranted.

Limitations

Homogenous samples within IPA are key in aiding transparency and exploration of psychological variables. Although the sample in this study was not entirely homogenous, similar levels of heterogeneity are noted within similar studies (Connell et al., 2014; Jones & Morris, 2013). Additionally, relative heterogeneity allowed useful discussion of ethnic differences, of value given the relative paucity of research in this area. Optimising rigour is

imperative within qualitative research, and is primarily related to the richness and depth of the data (Smith et al., 2009). Although efforts were made to ensure interview data was solely related to the upper-limb, it is acknowledged participants may have divulged information pertaining to more general stroke experiences, therefore data should be interpreted with some degree of caution. Further, although dyadic analysis was undertaken to augment the perception of the phenomenon on study and efforts to explore convergence and divergence between transcripts were made, it is acknowledged potentially conflicting themes may have been somewhat submerged.

Conclusions

Participants voiced negative experiences of upper-limb rehabilitation. Seemingly, this was associated with disappointment in upper-limb service provision, including inadequate information, reduced autonomy within decision-making and misplaced or persistent hope. Therefore, during acute rehabilitation, healthcare professionals should be aware of motivators for lower-limb rehabilitation and may wish to explore decision-making in conjunction with stroke survivors and caregivers, in further detail. The persistent stroke survivor and carer expectations of upper-limb recovery appear intrinsically formed and may negatively affect collaborative working between healthcare professionals, patients and carers, therefore highlighting the important role of adequate communication and information. Lastly, the experience of a dysfunctional upper-limb engenders a complex array of physical and emotional needs, which appear embedded within different

psychological constructs, requiring adequate long-term physical and, particularly, psychological community support.

Future research could explore therapists' perceptions of acute upper-limb rehabilitation, the necessary components of adequate community psychological support for both populations within ethnically diverse populations, and post-stroke service provision across a wider sample.

Implications for physiotherapy practice

- Stroke survivors and their carers identified an imbalance between upper and lower-limb rehabilitation during the acute phase of recovery. This was perceived to impact physical and psychological function and ongoing perceptions of the limb, resulting in ongoing needs, particularly community-based support.

- Loss of autonomy or control during early upper-limb rehabilitation and within decision making may detrimentally affect stroke survivors' experience of rehabilitation. Healthcare professionals may wish to explore decision making during acute rehabilitation in further detail.

- Persistent high expectations of upper-limb recovery and inadequate information may negatively affect collaborative working between healthcare professionals and patients, necessitating adequate and timely information and communication.

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Table 1. Stroke survivor characteristics.

Name[a]	Age (years)	Gender	Affected hand	TSS (mnths)[b]
David	56	Male	Right	92
Mary	74	Female	Left	71
Amy	45	Female	Right	14

Table 2. Caregiver characteristics.

Name[a]	Age (years)	Gender	Relationship	Employment status
Amelie	36	Female	Partner **(David)**	Mature Student
Neil	75	Male	Partner **(Mary)**	Retired
Dan	20	Male	Son **(Amy)**	Employed

a All names are pseudonyms
b Time since stroke (months)

Figure 1. Hypothetical chronological representation of master themes